Department of Developmental Services
Annual Family Support Plan
Fiscal Year '17 (July 1st, 2016 – June 30th, 2017)

Human Service Agency Overview of Family Support

A. Background

The Department of Developmental Services (DDS) has been providing flexible family support services since 1995 to children and adults who are eligible for services from DDS living at home with their families. This is the fourteenth Annual Plan for Family Support submitted by the Department as required by Chapter 171 of the Acts of 2002, "An Act Providing Support to Individuals with Disabilities and Their Families."

DDS is organized into four regions and 23 Area Offices managed by Regional Directors and Area Directors respectively, all under the auspices of Central Office. Each DDS region has a Director of Family Support. Area Office Service Coordinators provide assistance and supports to individuals/families, with a Children's Coordinator who usually works with children under the age of 18 years and their families, and a Transition Coordinator who usually works with individuals between the ages of 18 and 22 who are in the process of transitioning from school to adult services. Individuals over the age of 22 who have met the adult eligibility criteria for DDS services are assigned a Service Coordinator and participate in an Individual Support Planning (ISP) process.

B. Overview of Family Support

The primary goal of family support is to provide a variety of options to individuals with disabilities and their families that enable them to stay together and to be welcomed, contributing members in their home communities. The DDS Family Support system is based on the principle that individuals and families know their own needs. For this reason, and because of the individuality of each family, the range of services available under the program is broad. This approach allows families the flexibility to identify the resources that will be most helpful to support their family member in her/his home. The Family Support Centers and other family support programs are designed to be responsive to the dynamic and changing needs of the individual with a disability and his/her developmental stages throughout life within the family unit.

Guiding Principles for Family Support serve as the foundation for the delivery of services through the Family Support Centers and all of the family support program services funded by DDS.

Family support strives to achieve the goal of helping families stay together through:

- Developing families' natural capacities to meet the needs of family members;
- Offering additional supports such as staff resources, goods and services, and financial assistance; and
- Enhancing the capacity of communities to value and support people with disabilities and their families.

DDS receives specific funding designated for the delivery of family support services through the Family Support Appropriation Account in the state budget. The FY 2017 budget appropriation of $62,846,395 million includes an increase of $5 million dollars in expansion funding. The FY 2016 increase of $3.5 million dollars brought the family support appropriation account back to the pre-recession funding level pf FY 2009 before significant state budget reductions were made as a result of the nationwide economic problems. This incremental increase in funding across

multiple fiscal years is a positive direction, reflects understanding of the importance and need to better support families caring for a family member with a disability at home, and will enable DDS to provide more individualized resources to assist families in their caregiving roles. Of this total appropriation, approximately $52 to 53 million is for specific family support services, and the remainder for other community support services. A major area of focus with this new funding will be to provide a more robust array of in-home and community supports for older caregivers who are committed to care for their adult family member at home. The array of family support services provided with this funding is described in more detail in Section III, Family Support Resources and Funding.

A campaign on "Supporting Families" was initiated this past year by The Arc of Massachusetts with the assistance of many partners including Massachusetts Families Organizing for Change (MFOFC), the Association of Developmental Disability Providers (ADDP), and Advocates for Autism of Massachusetts (AFAM). The campaign developed information about the needs of caregivers, the impact of providing 24/7 care, and the cost-benefits to the state of providing supports to families as a means to avoid more costly out-of-home supports. This information was complemented by many powerful personal stories shared by families about the day-to-day challenges they face and the ways family support services and programs have made a positive and significant difference in their lives. The activities of this campaign contributed to an increased understanding of the need for and benefit of family support which was helpful in obtaining increased funding for these services in FY '17.

Currently there are 36,491 individuals eligible for DDS services living in the community, with 8,027 children under the age of 18, 3,752 individuals between the ages of 18 to 22, and 24,712 over the age of 22. Approximately 20,000 children and adults are living at home with their families. Since 2014 with the passage of the Autism Omnibus Act, the eligibility for DDS adult services was expanded to include adults with Autism Spectrum Disorders (ASD), Prader-Willi Syndrome, and Smith-Magenis Syndrome. Meeting the IQ (Intelligent Quotient) criterion is not a requirement for this group of individuals, but they must meet specific diagnostic criteria as well as the standard of having a Developmental Disability which includes substantial functional impairments in three or more of seven life areas. Since that time, 733 individuals with ASD have been found eligible for services, and 4 individuals with Prader-Willi Syndrome. This group of eligible individuals has access to an array of community support services including: employment/day services, family supports, in-home skills training and community integration supports, and individual supports for people who are living more independently.

C. Process for obtaining substantial input from families on current family support services

DDS uses multiple approaches, both formal and informal, to seek input and guidance from individuals with intellectual disabilities and their families in order to help assess the Department's current system of family support services, and help inform policy development and future directions. Over the past several years DDS, in partnership with family members and providers, has been engaged in a variety of initiatives to strengthen the information, resources, and assistance provided to families in their caregiving role that are directly responsive to priority need areas identified by families through a strategic planning process initiated in 2011, and described in the 2012 report *In Their Own Words: The Need for Family Support Services*." The important supports needed by caregivers and the benefits and cost-effectiveness of family support were identified. Families expressed the need for respite, access to flexible funding/stipend resources, increased options for social and recreational experiences, and easier access to information along with help navigating services. As documented in this report, Family

Support is 75% to 80% less expensive than providing services to an individual in an out-of-home residential placement.

A full copy of the report, *"In Their Own Words: The Need for Family Support Services" and the* plan "*Moving Forward in Enhancing Supports for Families: An Action Plan for Family Support,"* are available on the DDS website at: www.mass.gov/dds.

Several of the central and ongoing ways DDS obtains feedback and input from families and other stakeholders are described below.

The **Statewide Family Support Counci**l, comprised of parents from across the state who have, or recently had children and adult family members with disabilities living at home with them, provides a substantive and ongoing vehicle for input and consultation to the Commissioner on family support services, practices, policies, and needs. Council members have played integral roles in family support strategic planning processes, helped shape the procurement of family support services, been active participants in different workgroups, and will continue to have an important role in assisting DDS along with other stakeholders, in the implementation of specific recommendations and action steps designed to build a more comprehensive, coordinated and responsive system of supports.

There is regular information-sharing, discussion, and solicitation of input from the DDS **Statewide Advisory Council (SAC)** and the four regional and twenty-three area office **Citizen Advisory Boards (CABs).** These advisory groups play an important role in helping to inform and educate the public and other decision-makers about the needs of individuals and families and the importance and benefits of the flexible services and supports that are provided.

The Commissioner along with other leadership staff meet with representatives of other family and individual advocacy organizations to seek input and obtain feedback on services and future directions. This includes representatives from the Arc of Massachusetts, Massachusetts Families Organizing for Change (MFOFC), Advocates for Autism in Massachusetts (AFAM), Massachusetts Advocates Standing Strong (MASS), Massachusetts Down Syndrome Congress, and the Developmental Disabilities Council. Monthly meetings are also held with the leadership of the Association of Developmental Disability Providers (ADDP). Additionally, DDS leadership staff have been actively engaged with the Autism Commission to work on plans and implementation of key recommendations in the Autism Commission Report that was released in March 2013, and the more recent Autism Omnibus Act signed into law in 2014.

D. Focus Areas: Review of Activities and Accomplishments in FY 2015 and Proposed Initiatives for FY 2017.

The following section provides brief highlights of ongoing efforts as well as new activities the Department has undertaken this past year, and includes where relevant, initiatives for development in the upcoming fiscal year.

I. Family Empowerment

What is the agency currently doing to promote or enhance family input or direction in the development of agency policies and procedures, program development, and evaluation of services?

DDS seeks input from individuals and families about agency services and new directions both formally and informally through a variety of organized groups and mechanisms, and this has informed and helped shape programmatic directions and priority areas in supporting families caring for their loved one at home. Family members are central participants on the statewide

Self-Determination Advisory Board, and were integral members of the Advisory Committee for the Positive Behavioral Supports Initiative that helped explore and develop a framework for the implementation of Positive Behavioral Supports (PBS) throughout the DDS system.

Individuals with disabilities and family members participate on the Department's Statewide Quality Council to assist in reviewing evaluation data and information about the quality of services provided, and to identify areas for development as part of a continuous quality improvement process. Family member engagement, input and participation is central to many of the agency-wide initiatives the Department is embarked upon, such as the *Employment First: Blueprint for Success and Shared Living Initiative* so that the voices, preferences and concerns of families are understood and addressed as new service delivery approaches are pursued.

How will agencies change how they are currently doing business to make their agency and services more family-friendly and provide opportunities for families and individuals to have greater input and influence?

The family support services provided by DDS are based on the principles that individuals and their families are recognized as primary decision makers about their lives and supports, and options need to be flexible to be responsive to the unique needs, strengths and cultural values of families.

- DDS is in the process of reviewing and updating the *Family Support Guidelines and Procedures* which serve as the framework for the delivery of family support services, which includes specific guidance about the administration of individual flexible funding allocations/stipend resources and the goods and services that are allowable. DDS will seek input from family members and groups to address any areas of that need clarity and to help promote responsiveness and flexibility while balancing some of the requirements and restrictions.
- Two different approaches to engage in self-direction of services, the *Agency With Choice* model, or Participant-Directed Program services through use of a contracted *Fiscal Management Service*, are offered to individuals and families which allows them more control in service design, hiring of staff, and management of their budget. Regional positions have been established to help promote and support increased participation of families and individuals to engage in the direction of their own services- a powerful way to exercise their empowerment. Presentations on how these models work, and the successful experiences of individuals and families who engage in participant-directed services will continue to be offered on a regular basis, combined with other informational and resource materials to encourage use of self-directed service options. Ongoing education, support, and development of consumer-friendly informational materials will be provided.
- Two of the specialized programs for children/young adults, the DESE/DDS Program and the Autism Waiver Program, are structured to support family empowerment as they provide families the opportunities to direct service and budget planning to meet the needs of their child and family, and have a role in the selection of staff who will provide supports.
- The DDS Home and Community Based Waiver Programs for adults provide enhanced opportunities for individual and family empowerment, through increased choice in service providers, choice of service delivery method, and portability of services. Information and education continue to be offered through Service Coordinators along with other approaches to help ensure individuals and families are aware of the options

available, and to support them to exercise their rights and choices when they are involved in service planning

II. Family Leadership

What training opportunities does the agency currently offer to families/individuals that would enhance their repertoire of skills?

DDS funds five regional Family Leadership programs and partners with Massachusetts Families Organizing for Change (MFOFC) to provide education, leadership training, and mentoring for families of children and adults with disabilities. This training and mentoring is developed and provided by families who have a family member with a disability, an important feature of these programs. One primary vehicle for family leadership development is the sponsorship of a *Family Leadership Series,* which occurs across 6-8 days over a several month period. This past year, four regional Leadership Series were held providing leadership development to approximately 100 families. Graduates of this series frequently move into new leadership roles in a variety of capacities. Additionally, each of the regional programs sponsored a training series called "A Full Life Ahead" that offers monthly seminars for families on topics related to a variety of services and supports including transition planning, housing, employment, futures planning, and fostering friendships, and had more than 500 participants across the state.

This past year an Advocacy Boot Camp was created to meet the needs of families with young children (birth to age 10), with developmental disabilities, chronic illnesses, and or complex medical needs. Six in-person sessions were held with the content focused on building foundational advocacy skills so participants can empower their children to lead rich, meaningful, and exciting lives. Fourteen parents from all four regions of the state participated in this training opportunity and were also provided six months of peer mentorship to support them in navigating services and pursuing other resources to help their children lead fuller lives. Another new leadership opportunity offered this past year was a two-day Advanced Family Leadership event with 25 participants from across the state. Many family member participants were former graduates of the *Family Leadership Series.* Participants underwent an intensive learning experience with well-known leaders and experts in the human services field on ways to promote rich, meaningful lives with individualized supports. It has been an exciting and positive development to have available a more diverse array of leadership training options tailored to be more responsive to the needs of family member participants at different life stages and with different interests, needs and time.

Based on the premise that information is power, the DDS funded Family Support and Autism Support Centers provide an array of educational events and trainings on relevant topics of interest to families of both children and adults, These Centers are required to offer a minimum of six training events per year, with many offering additional training opportunities. Leadership development is also promoted through the Centers by facilitating parent networking and mentoring, sponsoring parent support groups and one-to-one parent connections, grandparent support groups, and sibling support opportunities.

What new ideas or proposals would the agency initiate to give families/individuals more opportunities to develop and/or exercise their leadership skills?

DDS has initiated a leadership development initiative, *Creating Our Commonwealth,* now in its second year, which provides training opportunities with both national and local experts on leadership skills and strategies, and best practices to promote social inclusion and community

membership for individuals with Intellectual and Developmental Disabilities through innovative supports and service design. This initiative involves approximately 100 emerging leaders that include family members, provider staff, DDS staff, and individuals with disabilities. In addition to these training opportunities, participants participate in regional group meetings, have access to other experiential learning opportunities, and are required to engage in the development of a project that applies their new learning in a way that will facilitate community membership and new relationships for a group of individuals with disabilities.

Families have opportunities to further develop and/or exercise their leadership skills as members of the DDS Statewide Advisory Council and twenty-three Citizen Advisory Boards, through participation in the DDS funded Family Leadership Projects, as well as through the Family Support and Autism Support Centers which are expected to actively engage families and seek their consultation to identify interests and needs in developing activities and the array of service options they will offer.

Individuals with intellectual disabilities and family members play an important role in making presentations as part of the Department's orientation and training for new staff which reaches both departmental and provider staff, as well as in other conferences and training events. Sharing information about their experiences, perspectives, and what is most supportive and helpful to them, provides both a positive learning experience for staff and a way for individual and families to expand their own repertoire of skills.

Peer Support and Family Training, two services available through the DDS Home and Community-Based Waiver Programs, provide interested and qualified individuals and families the opportunity to provide training and mentoring to others, as well as provide learning opportunities for self-advocates and families who want to enhance their own leadership skills.

III. Family Support Resources and Funding

What are the current resources/funding that the agency allocates to family support? What are ways that the agency provides flexible funding to families that allow them to customize their services?

DDS funds **Family Support Centers** across the state intended to establish a local community presence and act as a hub for offering a wide range of general family support services and activities to families of children and adults eligible for DDS services. Centers are expected to develop strong local affiliations and partnerships with other state and community agencies, become experts in generic resources and services, and work to maximize natural supports. Services provided include: information and referral, support groups, family trainings, parent networking and mentoring, facilitation of social/recreational events, among other activities. Centers also provide Service Navigation that includes individualized and comprehensive information, guidance, and support to families to address their needs, connect them to potential resources, assist with problem-solving and help them navigate the service system. Centers administer flexible funding/stipends to families who are prioritized to receive an individual allocation which can be used flexibly by families to purchase allowable services and goods as defined in the Department's updated Addendum to the Family Support Guidelines and Procedures. There are 34 Centers funded across the State with funding totaling approximately $9.4 million dollars. These Centers along with the Cultural/Linguistic Specific Centers described below provide some type of individualized assistance to about 10,000 families a year, plus reach many more through information and referral, trainings and recreational and community events.

Cultural/Linguistic-Specific Family Support Centers are designed to respond to the unique needs of specific cultural and linguistic family groups in specified areas or regions of the State. English is not the primary language for many of these families, and as a result they face linguistic barriers in accessing services and require more individualized and specialized assistance to learn about and access the service system. These Centers offer a similar array of services as the Family Support Centers described above. There are ten Cultural/Linguistic-Specific Family Support Centers with funding totaling approximately $980,000 dollars.

Autism Support Centers provide an array of information and referral services, resources, and supports to children with autism spectrum disorders ASD) and this past year expanded their focus to support families of adults with ASD and Developmental Disabilities who are part of the newly eligible population. The array of services and supports includes, but is not limited to, information and referral, family clinics, support groups, access to the latest information on autism, family trainings, parent networking and mentoring, and social/recreational events. There are five large and two smaller regional autism support centers funded at approximately $2.8 million dollars, which covers the community based initiatives and other center activities outside the Autism Waiver Program. They typically reach about 6,000 families a year with information and resources, and the community-based activities they offer reach about 2000 families from across the Commonwealth during the year.

Intensive Flexible Family Supports (IFFS) Programs are designed to help families who are experiencing severe stress which can lead to the child being at-risk of an out-of-home placement. Intensive case management services are provided to help families integrate the variety of available resources to support their family member in crisis, and flexible funding to purchase additional supports or goods. These program services, originally designed to assist families of children between the ages of 3 and 18, have been expanded to age 22 to be responsive to the emerging needs of the 18 to 22 age group of young adults living with their families. Annually, about 650 children and their families receive services through the 19 regional and area based programs across the State, funded at approximately $2.1 million dollars.

Medically Complex Programs support families who are caring for children/young adults up to the age of 25, with significant cognitive, physical, and complex health care needs who are living at home. Intensive medical wrap-around case management services are provided to help families integrate the variety of resources and supports they are receiving and offer flexible funding/stipends to assist the family in the purchase of additional supports and goods not covered by health insurance. This program complements and is supplemental to other MassHealth State plan and third party insurers. Annually, these programs provide services to about 375-400 individuals and their families. These five regionally based programs are funded in total at approximately $700,000.

There is currently one **Planned Facility Based Respite Program for Children** that offers planned, out-of-home respite services for children in the Central/West Region. This program provides short-term temporary relief for families, and include overnight, weekend, and/or vacation stays. Individuals are provided with a variety of recreational, social, cultural and/or educational activities during their stay. On average, 100 children and their families are able to utilize this service annually and the total funding amount is approximately $220,000.

In addition, the Department operates the **Medical Respite Home** in Southeastern, MA that provides an important resource for adults with complex medical, physical and developmental needs who require 24 hour, specialized nursing care, and their families. First opened in 2012 in response to the need identified by families for this service option, this program has continued to

evolve, and includes transportation, a variety of community-based activities, and other supports to assist individuals and families in using this service. Approximately 43 individuals and their families have been able to use this resource for a total of 872 overnight stays, providing important relief and respite for families and a new experience for the adults.

Family Leadership Development Programs provide education, mentoring and support to families. A major focus is a comprehensive and intensive family leadership series which provides information and education about "best practices" and helps families gain knowledge about policy making at the local and state level to assist them in assuming leadership roles in their local community and the disability community. There are five regionally based Family Leadership Programs funded for a total of approximately $400,000.

The Autism Division at DDS received $5.6 million dollars in FY 2016 to provide services and supports to children with autism. The Medicaid Home and Community-Based Services Autism Waiver Program served about 260 children under the age of 9 at any one point in time. The Autism Division also helps fund a specialty community program designed to train first responders called the Autism and Law Enforcement Education Coalition (ALEC}. This program remains a successful initiative which has received national recognition.

The Department of Elementary and Secondary Education & Department of Developmental Services Community Residential Education Program (DESE/DDS) is a successful collaborative initiative designed to provide supplemental supports to children/young adults determined to need services to prevent a more restrictive educational or out of home residential placement, or to assist families whose children are coming out of a residential placement. The intent of the program is to increase family capacity to support their child in the home and community, as well as to provide an individualized plan of supports that promotes skill building, independence, and social integration across the spectrum of the child's home, school and community. In FY 2016, the program continued to receive $6.5 million to provide capacity building supports and related services to about 572 participants across the year ranging in age from 8 up to 22.

FY 2017 Family Support Funding Increase

Based on consultative input from the Family Support Council and other stakeholders, the following priority areas have been identified for use of the expansion funding of $5 million dollars in the family support appropriation account this upcoming fiscal year: 1) provide expanded in-home and community support services to older family members who are continuing to provide care for their adult family member at home; 2) expand access to individual flexible funding/stipend allocations to families in need who have not been receiving funding support or can use increased resources to help them care for their family member at home, which continues to be one of the most important need areas identified by families; 3) add capacity to serve more families through the Intensive Flexible Family Support Services programs, both to possibly increase the number of 18 to 22 year olds who receive these services, and to offer more robust packages of wrap-around supports for some families in need to help them care for their family member at home; 4) Add staff resources to some selected local Family Support and/or Cultural/linguistic-Specific Centers where there is a need to build additional capacity, especially to assist in implementing supports for older caregivers and to administer individual flexible funding allocations. Use of this increased funding will be monitored regularly by DDS throughout the fiscal year. Periodic reports will be shared with the Family Support Council and other interested stakeholders.

IV. Accessing Services and Supports

What are current examples of ways the agency is educating families on how to access services in a timely and effective manner? What are some illustrations of different services and resources which promote good access to information and referral?

The DDS funded Family Support, Cultural/Linguistic-Specific, and Autism Support Centers provide Information and Referral services to families of children and adults within their geographic area. This includes assisting families to identify resources and service options available in their local communities, to learn about other financial and/or state services for which families may be eligible, and to provide guidance on how to navigate the service system. They use a variety of approaches to disseminate information to families, including email, list-serves, web-sites, on-line newsletters and training calendars, webinars, and social media, as well as create and maintain a "library" of resources. These Centers engage in a variety of outreach activities to connect with families in different venues who may benefit from their information and resource services, including early intervention programs, local school systems, health care providers and through other community based organizations.

Families are sent a 'welcome flier' with information about the Family and Autism Support Centers in their area at the time their son or daughter is found eligible for services, so if families are not already connected to a local Center it gives them the information to make that contact. This notice is made available in multiple languages to be responsive to families for whom English is not their primary language.

A 'Statewide Family Support Directory' is available to help families find the Family Support and Autism Support Center and other family support programs in their area to promote easier access to these resources. The Directory is widely disseminated through DDS, service providers, and is posted on the DDS website.

DDS has provided funding for a project called "Widening the Circle" to assist in expanding opportunities for friendships between individuals with and without disabilities and community participation through training and the development and distribution of information and resources. Key accomplishments include the development of a website with resource information, the delivery of over 100 "Introduction to Friends" presentations across the state reaching more than 2,500 people including parents, people with disabilities, and DDS and provider staff, as well as 'train the trainer' sessions.

DDS sponsored multiple training events this past year for family support programs and agency staff, all designed to promote capacity-building to enhance the supports and services provided to families across the life span. These events provided opportunities for staff to share information, promising practices, and new initiatives in specific topical areas, and fostered an opportunity for networking. About 500 staff participated in these different training events. Several sessions focused on information-sharing to promote a better understanding of the characteristics and support needs of individuals with Autism Spectrum Disorder, with a particular emphasis on how to be helpful to families in their role as caregivers while trying to promote the emerging independence of their adult family member. The presentations by parents at these training events were especially insightful and invaluable.

A successful statewide conference focused on the theme of "Supporting Individuals and families to Have Full and Meaningful Lives as Members of Their Communities" was held in May. The conference included a compelling keynote presentation on the power and potency of social capital by Al Condeluci from the University of Pittsburgh School of Social Work and School of

Health and Rehabilitative Services, which was very inspiring and motivating to participants. Family members played key roles as presenters in several break-out sessions sharing their experiences and insights on using social capital to successfully create meaningful membership in the community for their sons and daughters. A resource area provided helpful information and resources from a variety of organizations including the Aging and Disability Resource Centers, the Commission on Supporting Grandparents Raising Grandchildren the Federation for Children with Special Needs, etc.

Other ways DDS helps make services accessible to families is through funding support for New England INDEX, and specifically the Autism Insurance Resource Center which provides information, training and consultation about the Massachusetts Autism Insurance Law (aka ARICA). DDS helps disseminate information about this resource to families and staff through multiple strategies.
A variety of publications and informational materials are posted on the DDS web-site to help families learn more about services and how to access them.

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What new initiative(s) will the agency undertake to promote good local access to information and resources?

- The DDS Regional Intake and Eligibility teams engage in outreach and provide training to varied groups and organizations about the DDS eligibility criteria and process to help reach families who may need this information.
- DDS is reviewing the agency' web-site to identify changes and ways to make the site easier to navigate and the information more accessible.
- Forums to provide information, training, and resources related to transition from school to adult services to help families understand the process and learn about adult service options and service providers, will continue to be sponsored for families by all DDS Area offices in partnership with local Family Support Centers and/or other providers. A set of fact sheets on key topics related to planning for the transition from school to adult life are made available to families in these sessions and on our web-site. "*Important Transition Information Every Family Should Know*" is a set of 26 fact sheets available to families and can be used in a flexible way to help families build their knowledge and resources about all aspects of this transition process. These fact sheets are now available in Spanish as well.
- DDS will continue to fund and support the web-based Rewarding Work Respite Directory that provides a directory of workers and other resources related to accessing respite and hiring in-home support staff. Individuals and families who receive services through DDS can access this directory at no cost. This past year information and resources were expanded for individuals and their families who are directing their own services to assist them in their efforts to find workers. A new feature of this site involves the development of an automated job posting function that allows individuals and families to recruit workers in a way that is more customized and specific to their unique needs. It is expected this will be an easier and more successful approach for finding workers more efficiently that are a good match for the individual/family situation. The Rewarding Work web-site was already available through support from MassHealth for individuals and families to find Personal Care Attendants (PCAs), and was enhanced and further developed to be responsive to the needs expressed by families to help them find respite and other in-home support workers. In addition, several small pilot respite training projects are being explored and implemented to help expand the pool of respite workers and options for families.

V. Culturally Competent Outreach & Support

What are the current activities or services that the agency offers that ensure culturally appropriate access and supports to ethnically, culturally, and linguistically diverse families and individuals?

The Cultural/Linguistic-Specific Family Support Centers provide bi-lingual and bi-cultural assistance to identified groups of families for whom English is not their primary language. They are expected to provide broad outreach and are frequently called upon by other organizations to help provide interpretation and translation assistance to families. These Centers primarily provide services to families who speak Spanish, Chinese, Vietnamese, Khmer, Russian, Haitian Creole, Portuguese, and Cape Verdean Creole. In addition, all Family Support Centers and providers are expected to develop resources and capacity to do outreach and be responsive to the diverse cultural and linguistic communities in the geographic area in which they are providing services.

There are an increasing number of children and families from a variety of diverse cultural and linguistic communities who receive services through the Autism Waiver Program. Interpretation services are provided as an integral part of these in-home program services.

DDS makes available translated informational materials for individuals and families in multiple languages. Positive working relationships have been established with several entities that provide interpretation and translation services and they have developed a good understanding of disability terminology and concepts that lead to providing more culturally relevant and responsive information.

DDS will continue to offer training opportunities for family support and DDS staff focused on increased understanding of families from diverse communities and to learn more about resources and strategies to provide culturally respectful and responsive services. It is important to foster learning from staff at the Cultural/Linguistic-Specific Centers and provide opportunities to hear directly from families from diverse communities about their experiences and perspectives in raising a child with a disability, and from providers about the approaches they have developed and used to offer culturally responsive services. Through regional meetings DDS staff continue to work collaboratively with providers to share positive practices and support them as they further develop their capacity to provide services to individuals and families from diverse communities.

There are active statewide, regional and central office Diversity Councils that offer a variety of opportunities for education, training, and cultural experiences to promote increased understanding of different cultural and linguistic groups, and support the delivery of more culturally responsive services.

What new ideas/initiatives will the agency propose to outreach and meet the needs of culturally diverse families and individuals?

- Workshops and forums focused on the development of culturally responsive services will continue to be provided for Family Support providers and DDS staff, with an emphasis on being welcoming and making services accessible to families for whom English is not their first language, and sharing strategies, resources and local partnerships that have been effective.

- Specific opportunities to bring together staff from the Cultural/Linguistic-Specific Family Support Centers across the state with DDS staff and other family support programs will be provided to foster information-sharing, networking, and to identify ways to strengthen efforts to provide more culturally competent services to families.

VI. Interagency Collaboration

Department staff participate in various inter-agency activities with other Executive Office of Health and Human Services (EOHHS) agencies to promote more effective service delivery and to maximize resources. Regional and area office DDS staff participate in local inter-agency planning teams to promote more effective communication, and when there are individuals involved with multiple agencies, to work toward coordination and collaboration in service delivery. Representation on these teams usually includes staff from the Departments of Children and Families, Mental Health, Transitional Assistance and Public Health, and in some situations, representatives from local school systems.

DDS, in partnership with the Executive Office of Elder Affairs, other human service agencies and community organizations, has completed the sixth year of a federal ***Lifespan Respite Grant*** from the Administration on Aging. A unique aspect of this project has been the cross-disability/special needs focus across the lifespan. A statewide lifespan respite coalition has been established, a website with respite resources and information on varied respite options has been developed, and training approaches and innovative models to expand the network of respite providers available to caregivers continue to be identified, with the goal of helping to address the well documented and essential need for respite for caregivers providing daily assistance and care for family members with disabilities. A respite summit was held in June 2016 to strategically examine and identify respite resources, opportunities, gaps and need areas across the state, in order to develop goals and a comprehensive plan for future efforts to establish a more sustainable array of respite supports. This past year five mini-demonstration projects were funded to support the delivery of respite services to unserved and underserved populations, and a new grant application was submitted that if successful, will provide funding for additional mini-grants.

DDS staff have also collaborated with staff from Elder Services, including the Aging and Disability Resource Centers (ADRC), and the aging network across the state to better understand the needs and resources to support the aging population of individuals served by DDS which has increased significantly in recent years. This partnership led to the development of a number of joint training and service initiatives, including funding for the creation of 13 Memory Cafes across the state to provide enriching experiences and support to older individuals experiencing memory loss and their caregivers. DDS will expand this partnership in the upcoming year as we focus on providing more support and resources to older family members who are continuing to be the primary caregiver for their adult son/daughter at home.

DDS leadership staff have been active members of the **Autism Commission** and have been working in partnership with other state agencies, advocacy groups and other stakeholders to support implementation of some of the key recommendations identified in the report that was issued in 2013 and to implement provisions of the Autism Omnibus Act of 2014. Many different DDS staff are participating in the varied workgroups that have been established to address the goals and need areas outlined in the Commission report. A strong inter-agency partnership has developed with the Department of Mental Health to better support adults with Autism Spectrum Disorder and Developmental Disability, many of whom are living with their families and experience co-occurring mental health issues.

DDS continues to work collaboratively with the Office of Medicaid, and the Departments of Mental Health and Children and Families, on the implementation of the **Children's Behavioral Health Initiative** (CBHI). An area of ongoing attention and focus has been to determine ways these services can be more responsive to the needs of children with autism spectrum disorders and what will support capacity building in this area. DDS works with partners to offer training and make information available for agency staff and family support providers so they are knowledgeable about the eligibility criteria and service options available in order to facilitate access to these services for children and families who may be eligible. DDS has also worked closely with MassHealth to share information on the **Applied Behavioral Analysis (ABA) service** that is now available through the State plan to help facilitate access to this service for children who are eligible and can benefit from this service

Department staff participate in **Unified Planning Team** meetings when requested for individuals who are eligible for DDS services, consult to EOHHS Unified Planning Teams for children who are not eligible for DDS services, and also continue to participate on the *One Child, One Plan* EOHHS initiative. DDS family support staff and children and transition service coordinators are collaborating with the Department of Public Health Care Coordination Program to help facilitate planning and smoother transition from school to adult life for individuals with significant and complex medical, physical, and developmental needs.

What new activities or initiatives does the agency propose to demonstrate the above goals?

- DDS staff will continue to work closely with the Executive Office of Elder Services on a variety of initiatives including supports for older caregivers, services and resources for individuals with ID who are aging, and in implementation of the Memory Café's. This will include planning of joint training sessions, sharing of resources, and development of local partnerships. DDS will also continue to collaborate with Elder Services and other human service and community organizations, family members and individuals to successfully implement the federal Lifespan Respite grant, support the Massachusetts Lifespan Respite Coalition, and promote use of the Rewarding Work Respite Directory.
- DDS and DMH will continue to develop and implement joint agency plans to better support adults with ASD who also experience other mental health challenges.
- DDS is participating in a renewed state agency collaborative effort with The Commission on the Status of Grandparents Raising Grandchildren. The Program Coordinator from the Commission participated in the resource area at the DDS annual family support conference and connections are being made between the family support providers who host grandparent support groups with the initiatives and outreach activities of the Commission.
- Following a discussion between leadership staff at MassHealth and DDS along with members of the DDS Family Support Council, there is ongoing communication and coordination on strategies to address several need areas that were identified to better meet the health care and support needs of individuals with other significant medical and physical challenges. Priority areas include approval and processing time for durable medical equipment, quality of diapers and other absorbent products, exploring ways to better utilize wheelchair repair expertise that is available in the DDS facilities, and improved customer service.
- DDS will continue to work in partnership with the Office of Medicaid in the implementation of the Home and Community Based Waiver Programs for adults and the Autism Waiver Program for Children.